EDITORIAL

Improving end-of-life care for patients with chronic heart failure

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The epidemic of heart failure and its human and economic costs are continuing to grow. Chronic heart failure is the major cause of morbidity and mortality in the Western world, and is the only cardiac condition increasing in prevalence.[1] It is primarily a condition of ageing, has a greater mortality rate than many cancers, and an equivalent symptom burden and severity. Most of the usually older people with heart failure therefore have short lives remaining of extremely poor quality.

Studies of patients with heart failure, lay-carers and health professionals have shown that patients have a poor knowledge and understanding of their condition and prognosis, that healthcare needs are poorly addressed, and that service provision, coordination, and uptake and continuity of care are suboptimal.[2–7] Doctors describe poor quality of care for patients, and identify that predicting the illness trajectory is much harder in severe heart failure than in cancer.[3]

Thus, it is not surprising that there is a growing recognition of the need for a better experience of end of life, and calls for palliative care to be extended to and integrated into the care of patients with heart failure.[8–10]

PALLIATIVE CARE

Chronic heart failure typically results in progressive debilitation, a deteriorating quality of life and distressing symptoms, especially at the end of life.[11] The aim of palliative care is to provide active holistic care to patients with advanced, progressive illness. The management of symptoms and the provision of psychological, social and spiritual support are paramount, the goal being the achievement of the best quality of life for patients and their families. Importantly, palliative care is defined as an approach that all health professionals should be able to apply to their clinical practice, calling on specialists in palliative care where necessary for patients with particularly complex needs, although a recent survey found that specialist palliative care services for patients with heart failure vary widely.[12]

INTEGRATING PALLIATIVE CARE INTO HEART FAILURE CARE

Palliative care for patients with heart failure has the potential to play a central role in relieving suffering and distress, for both the patients and carers.[13] However, how it is routinely integrated into care for patients with heart failure is less straightforward, although models of care, which focus on quality of life, symptom control and psychosocial support for patients and their families, have been suggested.[5 9 10 13] Models should take account of strategic planning across primary and secondary care sectors, involve healthcare and social care services and specialist palliative care providers, and be informed by the needs, experiences and preferences of patients, carers and health professionals.

In the study by Selman *et al*[14] in this issue of *Heart* ***(see article on page 963)***, the objective was to generate guidance and recommendations for improving end-of-life care in chronic heart failure. Although the findings largely concur with those of other studies,[2–7] they do raise the importance of patients and family carers being informed and consulted about their end-of-life preferences, the need for staff training and education, and the need for mutually agreed palliative care referral criteria and care pathways.

The importance of good communication cannot be emphasised too much. Open and sensitive communication and close attention to symptom control are the basic principles of palliative care.[9] Training in these techniques should be mandatory for all those involved in end-of-life care. Without open acknowledgement of the patient's condition and likely prognosis, it will be impossible to discuss any concerns the patient or their family may have, or allow them time to set their affairs in order or to make end of life plans.

The views of patients with heart failure and their carers on how they would prefer to be managed should be sought and heeded, including the opportunity to discuss death and dying with those caring for them.[2]

THE ROLE OF NURSES

Recommendations made by Selman *et al*[14] include clarification of specialist roles and when to refer, and routine assessment of the need for palliative care. Perhaps these are areas best addressed by the specialist heart failure nurse, particularly when there is a perception among doctors that palliative care should be the concern of nurses.[7] Heart failure nurses are well prepared to help bridge gaps in end-of-life care, especially for those patients who would prefer to die at home. Two recent examples describe the provision of local palliative care services for patients with heart failure, in which specialist heart failure nurses play a central role.[15 16] One service adopted a shared care approach by a cardiologist and palliative care

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physician, with the heart failure nurse specialist acting as a key worker and liaising between primary care, secondary care and hospice services.[15] The other adopted a collaborative model between community-based heart failure nurse specialists and existing palliative care services, with the heart failure nurses remaining the key worker throughout the illness.[16] These studies present a limited, though encouraging, picture, and are certainly an improvement on the current lamentable state of service provision.

WHERE NEXT?

It is likely that most of the palliative care needs of patients with heart failure will be met by existing care providers, be they specialist nurses, primary care teams or hospital staff improving their own palliative care skills, with support from and access to specialist palliative care, rather than by hospices and specialist palliative care services alone. However, there is a need for specialists in palliative care and those in heart failure or cardiology to work together to improve the standard of generic palliative care offered to these patients. Patients with complex symptoms, or patients or carers with severe psychological distress or social needs, may need to be referred to specialist palliative care, which may also be able to offer family support, particularly for young families with children, when a patient's prognosis is poor.

CONCLUSION

Although there are encouraging signs that the state of end-of-life care for patients with chronic heart failure is improving, much remains to be done. Greater consideration needs to be given to education and training in communication and symptom management, clarification of roles and referral systems, and to coordination and continuity of services. A proactive approach designed to meet the specific needs of patients and carers is required.

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